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Bon Appétit....Without Wheat

New research finds “rare” ailment found quite common

By Ali Bassett

Karen Robertson’s 19-month old son was losing weight and throwing up daily. His belly was hard and enlarged. She was very concerned. After multiple trips to the pediatrician and a pediatric gastroenterologist, the surprising culprit was found: wheat, the so-called staff of life!

Sam Robertson had celiac disease, a little-known illness that often goes undiagnosed. It causes the body’s immune system to attack gluten, found in wheat, rye, barley, spelt, kamut, and other related grains. If left unchecked it damages the small intestine to the point that the body can no longer absorb nutrients from food.

So, before Sam could even enjoy a bite of cake on his second birthday, he was destined to a life without...without bread...without cookies...without birthday cake. That was until his mother got to work.

Over the last six years, Karen Robertson has researched, tested, and written recipes that are gluten-free. She recently compiled them into a cookbook entitled *Cooking Gluten Free! A Food Lover’s Collection of Chef and Family Recipes Without Gluten or Wheat* (Celiac Publishing, 2002). A labor of love, this beautiful cookbook is filled with over 190 gluten-free recipes – everything from sushi to pizza. Robertson shows how easy it is to create delicious, healthy baked goods using a special flour mix that she combines with amaranth, teff, buckwheat, or quinoa flour. Also included are recipes contributed by celebrated chefs around the country, many of whom are James Beard award winners or have been featured in food and wine magazines. Beautifully illustrated in watercolors by her mother-in-law, J. Diane Robertson, the book contains a wealth of information on finding gluten-free products and patient support organizations.

New research, recently published in the *Archives of Internal Medicine*, (“Prevalence of Celiac Disease in At-Risk and Not-at-Risk Groups” Alessio Fasano M.D., Feb. 10, 2003), shows that in the group tested representing the general population 1 in 133 people tested positive for celiac disease. This represents 1.5 million people in the United States. About 40 percent of the afflicted show no symptoms though they may be showing a loss of bone mass, infertility, or subtle mood changes. Diagnosing the disease can be very tricky. It is sometimes mistaken for other conditions including irritable bowel syndrome, Crohn’s disease, ulcerative colitis, diverticulosis, intestinal infections, chronic fatigue syndrome, and depression. Because the disease has a genetic component, immediate blood relatives are prime candidates. Even though Karen’s daughter didn’t have any of the symptoms associated with celiac disease and was apparently healthy, she also tested positive for the disease. If she continued to eat gluten, she would be at risk later in life for other autoimmune disorders such as lupus, thyroid disease, rheumatoid arthritis, etc.

If her son hadn't exhibited the symptoms of celiac disease, Robertson might not have ever known anything was wrong with either child until the damage was done. She discovered some people show no symptoms while others become extremely sick when gluten is introduced into their system. Often a trigger such as surgery (as in her son's case), pregnancy/childbirth, severe stress or a virus can exacerbate the condition enough to make the symptoms noticeable.

What exactly is celiac disease?

The disease was discovered in 1888 by a British doctor who determined a connection to diet. Then during World War II a doctor in the Netherlands noticed that during wartime rationing of bread, children afflicted with the disorder improved and later relapsed when bread was introduced back into their diet. In a normal small intestine there are fingerlike protrusions called villi that absorb nutrients from food. The immune system of a person with the disorder will attack gluten when it comes into the body and, in turn, any villi that have absorbed it. The villi become inflamed, eventually flattening out, even disappearing. Once this happens the body can't absorb the nutrients needed to live. Typical symptoms include diarrhea, abdominal cramping, and vomiting. Untreated this can lead to malnutrition. Atypical symptoms include anemia, infertility, osteoporosis, and seizures. In children it can stunt growth and cause behavioral changes. According to Alessio Fasano, M.D., Co-Medical Director of the Center for Celiac Research at the University of Maryland, "Celiac disease is the most common genetic disease in Europe. Due to genetics and based on recent studies, in the United States it is estimated that 1 in 133 have celiac disease even though only a fraction have been diagnosed to date."

A lesser-known form of celiac disease is Dermatitis Herpetiformis (DH). This rare form of gluten sensitivity couples the intestinal damage of celiac disease with an itchy, burning skin rash. DH is caused by reactions to antibody complexes that are deposited under the skin. Because the rash can be treated with the drug Dapsone, a gluten-free diet is not always followed. Unfortunately this can lead to an increased risk for lymphoma in the small intestine due to continual damage to the villi. DH is a lifelong illness and even once a gluten-free diet is adopted it can take a long time for the rash to disappear.

The first step in making a proper diagnosis is a blood test. A person with celiac disease has excessive levels of certain antibodies in their blood. Once a positive blood test is confirmed the next step is a biopsy of the small intestine. However, finding a physician who can accurately diagnose celiac symptoms can be challenging. "American doctors have the knowledge and the training, but we're not testing for celiac disease," Dr. Fasano observes. "The problem is that the disorder causes many vague symptoms, and we are not used to thinking about celiac disease as the cause. We need to change our thinking."

With a positive diagnosis the road to recovery begins with a totally gluten-free diet. By eliminating gluten, the small intestine will steadily heal and begin absorbing essential nutrients. Unfortunately this is also the hardest part. Besides the obvious offenders: wheat, rye, spelt, triticale, kamut, and barley-- gluten is hidden in all kinds of foods ranging from ice cream to soy sauce. Oats, which don't contain gluten, are often avoided

as well due to the possibility of cross contamination in processing. Adhering to a gluten-free diet can be a tremendous challenge. Cookbooks such as Robertson's raise awareness about celiac disease, but best of all, they mean a life filled with cookies, bread and birthday cake!